Growth attenuation therapy: Experiences, attitudes, and practices of genetic counselors

by

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ABSTRACT

Growth attenuation therapy (GAT) is a controversial intervention used to halt the growth of children with profound disability with the intention of facilitating long-term care by the child's guardians. There are no nationally accepted clinical guidelines to direct clinicians how and under what circumstances to initiate a referral for GAT, and clinician attitudes and practices regarding GAT are poorly understood. Pediatric genetic counselors often serve a role helping guardians make decisions about treatments and coordinating care for their child. In this study, genetic counselor attitudes and clinical behaviors regarding GAT were explored through a survey of 62 pediatric genetic counselors and semi-structured interviews with eight genetic counselors who had considered or discussed GAT for a patient. GAT is a divisive intervention for genetic counselors, and attitudes toward GAT diverged the most regarding the degree to which GAT infantilizes children and the extent to which choosing GAT for a profoundly disabled child infringes on that child's autonomy. Most genetic counselors felt some discomfort about discussing GAT with a family whether due to their limited knowledge of the intervention or their opposition to its use. However, participants also emphasized genetic counselors' unique skillset as a bridge between medical doctors and patients, and as a source of therapeutic counseling for guardians facing difficult care decisions which may be called upon in discussions of GAT.

PREFACE

This research was inspired by a pair of six-foot-tall, 40+ year old, thoughtful, sincere parents raising a sweet, loving five-year-old girl with severe Angelman syndrome. If it weren't for hearing their story and seeing the genuine, empathic counseling from their genetic counselor, I never would have dived into understanding this complex topic. It's true that sometimes no option is ideal, but I have great respect for the parents, clinicians, ethicists, lawyers, and disability advocates who are all working toward providing compassionate care to children with profound disability.

I'd like to thank the people and organizations that made this work possible with as little additional stress as possible. The Intramural Research Program of the National Human Genome Research Institute sponsored this research so I didn't have to scramble for funding, and the entire executive committee of the GCTP eagerly provided support and advice for its development. Special thank you to Debra, Jill, and Lori for putting in the most time and energy to help me clarify my ideas and present this work in the best way possible.

Thank you to Mom, Dad, Julia, Eamon, Earl, and Mel for giving my head and heart a place to rest when I needed somewhere to stay near a rotation, for offering a kind ear to listen to me vent, for offering fantastic advice.

I will never be able to thank Mason enough. For supporting me throughout this program with encouraging words, warm hugs, and appropriately-timed cupcakes, for always having the right thing to say, for being strong when I could not, and for being my very best friend: thank you.

Finally, thank you to my participants. I've learned so much about how clinicians think about controversial topics and how they operate within their teams, and I would not be here without the genetic counselors who were willing to be vulnerable and honest.

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INTRODUCTION

Growth attenuation therapy (GAT) is a medical intervention by which the growth of a child may be arrested at a young age using an oral, injected, or patch-delivered estrogen supplement (Venn et al., 2008). In the past decade, this treatment has received attention as a way to facilitate independent care for guardians of non-ambulatory children with severe physical and cognitive delays. First reported in 2006, the use of GAT to halt the growth of a six-year-old girl with profound cognitive and physical disability was estimated to reduce her adult height by 25.4 cm (Gunther & Diekema, 2006). Venn and colleagues have reported that GAT has no effect on those who undergo treatment at a bone age of 15 or older, and that greatest height reductions occur when guardians decide whether their child will undergo GAT by the time they are 10 years old (2008). Among medical professionals, ethicists, legal professionals, and guardians, GAT raises a debate over such issues as quality of life, autonomy, and human dignity. Proponents write that growth attenuation, sometimes paired with hysterectomy and/or breast bud removal, is a way to help aging guardians care for their children as they grow without the need for outside or institutional care (Diekema & Frost, 2010; Kerruish, 2016). Supporters emphasize an improved quality of life associated with GAT: if a child's growth is halted, they are easier to carry, change, bathe, and bring on vacations, and they may never need a stranger to take care of them regularly.

The American Association on Intellectual and Developmental Disabilities took a strong stance against GAT, renaming it "ethics-attenuation intervention" for the purposes of their position statement (Bersani, et al., 2007). Critics of GAT warn that its use infantilizes the treated children, harkening to an age of eugenics and human rights violations of those with intellectual disability. From this perspective, GAT violates the

autonomy and dignity of children for the purpose of easing the burden on the guardians but has no clear benefit to the children themselves (Ouellette, 2009). Similar concerns have arisen in debate about other interventions intended to ease care and increase quality of life for children with profound disability, such as sterilization, breast bud removal, and restricting weight to the low end of healthy through diet (Cureton & Silvers, 2017; Diekema & Frost, 2010). These interventions have a longer history of study and research than GAT, and GAT's use is complicated by the fact that sometimes interventions such as sterilization and breast bud removal are implemented in conjunction with growth attenuation.

Critics also express concern about GAT's unknown efficacy and side effects when used for young children, and that its use amounts to an experimental medical procedure on disabled children who cannot consent (Brosco & Feudtner, 2006). Follow-ups with healthy women who were historically treated for tall stature as adolescents revealed no significant long-term side effects from GAT However, there is a known risk for short-term pain and thrombosis, and any additional risks based on treating at a younger age are unknown (Pyett et al., 2005). Given its only recent use for children with profound disability, there has not been the opportunity for a longitudinal comparison of treated and untreated children in categories such as overall health, quality of life, and length living at home under the care of their guardians. These knowledge gaps have contributed to the controversy surrounding this potential intervention.

GAT in the medical community

Currently, there are no nationally accepted clinical guidelines that outline the process by which medical professionals should discuss GAT with guardians, in which cases GAT is appropriate or inappropriate, and how treatment should progress. Furthermore,

professional societies such as the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, and the American College of Medical Genetics and Genomics have demurred from publishing position statements. Clinicians continue to field questions and requests for GAT without guidance, and it is likely that these discussions will become more frequent as GAT becomes more well-known to both guardians and clinicians.

In a survey of 284 American pediatric endocrinologists, approximately one in three respondents had been asked about GAT by parents of children with profound physical and cognitive disability, and approximately one in ten respondents had prescribed GAT (Pollock et al., 2015). There have been no formal surveys of American pediatricians, endocrinologists, geneticists, or genetic counselors that assess attitudes toward GAT and how those attitudes affect the ways in which medical professionals discuss, prescribe, and facilitate the treatment.

Independent commentaries provide some insight into the attitudes of medical professionals toward GAT. Some pediatricians in the United States and New Zealand have recommended that a discussion of GAT be initiated by the child's practitioner as anticipatory guidance for one of many treatments that some guardians may wish to consider (Allen et al., 2009; Wrigley et al., 2017). Other medical professionals have made statements decrying GAT as an inappropriate and unethical therapy for children with profound disabilities (Tan & Brassington, 2017). In one study of medical professionals from New Zealand, approximately the same number of respondents believed that GAT was an inappropriate therapy for children with profound physical and cognitive disabilities as

those who felt that GAT should be offered to all guardians of children with those disabilities (Wrigley et al., 2017).

Due to the starkly contrasting attitudes toward GAT, developing a comprehensive position statement or clinical guideline proves difficult. In 2010, a report was published of a 20-person working group formed to deliberate the ethical and policy considerations associated with GAT (Wilfond et al.). This diverse group of professionals included experts in medicine, law, bioethics, and philosophy, as well as multiple individuals who were either personally affected by significant disability or had family members with a profound disability. Ultimately, no consensus was reached, but instead the group presented a "moral compromise": GAT is acceptable in some circumstances, but should be preempted with a structured decision-making process, meeting set eligibility criteria, and the involvement of an ethics committee. The specific format for these processes was not specified, but a preliminary guideline for eligibility criteria was suggested: appropriate candidates would be both non-ambulatory and non-communicative, and the condition must be presumed to be permanent. These suggested guidelines were not satisfactory to all members of the working group, but they are generally in line with the suggested guidelines for similarly controversial treatments such as sterilization of minors with profound disability (Committee on Bioethics, 1999; Paransky & Zurawin, 2003). Whether genetic counselors are aware of the results of this working group or if their practice is influenced by it remains as unknown as the impact of genetic counselors' personal views on their discussions with guardians.

Genetic counselors and GAT

As genetic testing technologies advance – particularly whole exome sequencing –, geneticists and genetic counselors may become a more common part of the care team for families seeking a diagnosis. It is likely that genetic clinicians who disclose diagnostic and prognostic information to guardians will begin to face questions about GAT more often (Kuperberg et al., 2016). Genetic counselors have the potential to play many roles for a family affected by disability. They may see the same client annually or more frequently, participate in care coordination, and serve as a bridge between the families and their medical team. Genetic counselors in the pediatric setting generally work in tandem with a pediatric geneticist, and although the genetic counselors themselves may not sign off on referrals, their unique relationship with the family and the physician has the potential to impact care. A genetic professional's attitude toward and mode of addressing the option of GAT may influence the decision-making process for the options available to guardians and their children.

In a 2007 study of how religion and conscience inform clinical practice surrounding controversial treatments, 14% of responding physicians reported that they would not inform patients of all legal medical options if the physician opposed one or more of the options on moral grounds, and 29% of responding physicians reported that they would not refer patients to a physician who would provide a controversial service with which they were opposed (Curlin, et al.).

Genetic counselors are known to at times face moral value conflicts with clients. However, much of the research into how genetic counselors manage these conflicts focuses on the prenatal setting, where decisions about morally-laden options such as prenatal

genetic testing, sex-selection, and termination are common (Silver et al., 2007). Genetic counseling as a field was founded on the concept of non-directiveness, which espouses separating one's personal values from professional work (Clarke, 2017). If subscribed to, non-directiveness suggests that a genetic counselor's attitudes toward controversial medical options should not affect the way they discuss those options and referrals with clients. In a series of interviews with 34 genetic counselors on the controversial topic of terminating a healthy pregnancy due to the fetus' sex, most genetic counselors would refer clients to resources or discuss this option despite their personal feelings on the morality of the practice. Other responses to this request from clients included the genetic counselor voicing her objections to the practice, refusing to refer based on institutional guidelines, or requesting that a different counselor work with the couple (Burke, 1992).

A recent survey of genetic counselors regarding non-medical sex selection through pre-implantation genetic diagnosis technology revealed that although most genetic counselors did not support this practice and felt discomfort discussing the option, in practice they supported the right of couples to use this technology for any reason (Yu, 2015). Respondents to Yu's survey also indicated concerns about the role of genetic counselors in discussing these options, which suggests a desire for guidelines at an institutional or national level. One function of the present study is to assess if there is a perception of a similar need among genetic counselors for guidelines regarding GAT.

A genetic counselor's perspective on the ethics of a practice has the potential to affect the care that a client receives, but it is unclear how or to what extent conversations about GAT may be influenced by how genetic counselors feel about GAT. How genetic counselors view and conduct discussions about GAT is particularly interesting as genetic

counselors have unique education in understanding the decision-making and adaptation process for families affected by disability. Genetic counselors frequently serve as care coordinators and patient advocates and may have unique contributions to the ethics discussion surrounding GAT. Understanding how genetic counselors approach GAT will provide a clearer picture of how these conversations are conducted in the pediatric genetics setting. The role that genetic counselors have in the pediatric setting regarding treatment and whether genetic counselors' attitudes toward GAT affect their willingness to discuss the option may have direct impacts on the accessibility of GAT for families. Genetic counselors are also likely to have insight into practices or guidelines regarding GAT that are followed by their teams and institutions that may affect referrals to GAT.

Conceptual Frameworks: The Four Topics and the Zone of Parental Discretion

Four principles of biomedical ethics underlie ethical decision making in medicine: beneficence, non-maleficence, justice, and autonomy (Beauchamp, 2013). Based on these principles, Schumann and Alfandre developed the Four Topics approach to clinical decision making (2008). Using this approach, clinicians are recommended to consider four broad topics which offer a series of specific considerations whose answers depend on the details of each unique case (See Figure 1).

Topic	Principles	Sample Questions	Additional GAT Questions
Medical Indications	Beneficence Non-maleficence	• What is the diagnosis and prognosis? • What are the goals of treatment? • What are the probabilities of success? • What are the plans in case of therapeutic failure?	• How severe are the child's disabilities? • To what degree might adult height be reduced? • What are possible side effects, and what is the likelihood of those side effects?
Quality of Life	Beneficence Non-maleficence Autonomy	• What physical, mental, and social deficits is the patient likely to experience from the treatment? • What are the prospects, with or without treatment, for a return to normal life? • Is the patient's present or future condition such that their continued life might be judged as undesirable? • Are there biases that might prejudice the provider's evaluation of quality of life?	• How might the child's life and/or care be affected by their expected adult height? • How might the child's life and/or care be affected by GAT treatment? • Is there a plan in place for care if the family forgoes treatment?
Contextual Features	Justice	• Are there family issues that might influence treatment options? • Are there religious or cultural factors? • Are there problems of allocation of resources? • How does the law affect treatment decisions?	• How have the guardians talked about the use of GAT? What are their motivations? • What resources are available to the guardians to facilitate care? • Is clinical research a provider motivation for supporting GAT?
Patient Preferences	Autonomy	• Is the patient mentally capable and legally competent? • Has the patient been informed of benefits and risks? • Has the patient expressed prior preferences (eg, advance directives)?	• How are the child's guardians managing the decision-making process? • To what extent are the guardians incorporating the child's needs into the decision-making process? • Are the child's guardians making the decision without undue outside pressure?

Figure 1. The Four Topics approach to ethical decision making in medicine.

Even after thoroughly addressing all four topics, clinicians may disagree about the weight that should be placed on the values captured by the questions. The ultimate decision about whether to assist in initiating GAT is unlikely to be with a genetic counselor alone. Certainly, the geneticist with whom the counselor works is likely to be involved in any discussion of GAT, and there may be a larger team, pediatric endocrinologist, or an ethics committee involved in cases in which guardians desire GAT but clinicians are unsure. These teams are faced with determining if the guardian's wishes should be denied.

One recent tool put forth to help clinicians assess whether a denial is appropriate is the Zone of Parental Discretion (Gillam, 2016). Rather than attempting to determine the course of action that is in the child's "best interests," which can be nebulous as it is perceived differently be different individuals, Gillam asserts that clinicians should strive only to determine whether the course desired by parents or guardians would be harmful to the child. Gillam defines "harm" in the context of this tool as any "serious setback of interests," which include components of well-being such as continued life, freedom from pain, relationships with others, and experience of happiness. The Zone of Parental Discretion acknowledges that at times the options available to a child and their family may all be sub-par, but any decision that does not harm the child – even if it is not considered the "best" course of action by clinicians – is permissible. This tool still leaves room for interpretation about the meaning of "harm," and "serious", however. As a result, two clinicians using the Zone of Parental Discretion may come to two different conclusions about whether GAT is appropriate for a child.

Because there are no national guidelines for addressing requests for GAT, clinicians such as genetic counselors may refer or deny referrals for GAT based on the dictates of

their own moral frameworks. It remains unclear, however, how genetic counselors conceptualize the ethics of GAT, if there is pressure from their field or institutions to support or reject GAT, or if they even view the discussion of GAT for children with profound disability as an ethically distressing event.

Significance

Given the conflicting views on the ethics of GAT for children with profound disability, clinicians faced with helping families navigate the decision-making process would likely benefit from health organizations and institutions developing guidelines for its use. Establishing guidelines with which all stakeholders largely agree has proven difficult. Until guidelines are developed, clinicians must use their own judgement to determine procedures for assessing when GAT may be appropriate for children with profound disability.

Genetic counselors have a unique medical perspective in that they spend significant amounts of time with families in the pediatric setting, serving as patient advocates, care coordinators, and as counselors to facilitate decision-making and adaptation in families affected by disability. As genetic technologies advance, it may become more common for genetic counselors to face the task of informing guardians that genetic analysis predicts that their child with profound mental and physical disability will never learn to walk, speak, or feed themselves. As knowledge of GAT grows, more guardians are likely to consider its use as a way to independently care for their child for as long as possible. It is likely that genetic counselors will face more discussions about GAT in the near future as guardians become familiar with GAT and as exome sequencing technology increases in use. Understanding genetic counselors' perspectives on the

practice will lend insight into how these discussions take place and how they may take place in the future. The purpose of this study was to understand the extent to which genetic counselors are aware of and participate in conversations surrounding GAT, as well as their attitudes toward the use of GAT and other controversial interventions in the pediatric setting. This study also assessed genetic counselors' interest in guidelines regarding counseling for controversial interventions, and what would be useful to include in such a guideline.

Growth attenuation therapy: Experiences, attitudes, and practices of genetic counselors

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INTRODUCTION

Growth attenuation therapy (GAT) is a medical intervention used to arrest the growth of a child at a young age using an oral, injected, or patch-delivered estrogen supplement (Venn et al., 2008). This treatment has received recent attention as a way to facilitate independent care for guardians of non-ambulatory children with severe physical and cognitive delays. First reported in 2006, the use of GAT to halt the growth of a six-year-old girl with profound cognitive and physical disability was estimated to reduce her adult height by 25.4 cm (Gunther & Diekema, 2006). Venn and colleagues have reported that GAT has no effect on those who undergo treatment at a bone age of 15 or older, and that greatest height reductions occur when initiated before the age of 10 (2008). Among medical professionals, ethicists, legal professionals, and guardians, GAT raises a debate over such issues as quality of life, autonomy, and human dignity.

Proponents write that growth attenuation, sometimes paired with hysterectomy and/or breast bud removal, is a way to help aging guardians care for their growing children without outside or institutional care (Diekema & Frost, 2010; Kerruish, 2016). Supporters the opportunity to improve quality of life: if a child's growth is halted, they are easier to carry, change, bathe, and bring on vacation, and they may never need a stranger to take care of them regularly.

Critics warn that GAT infantilizes the treated children, harkening to an age of eugenics and human rights violations of the intellectually disabled. From this perspective, GAT violates the autonomy and dignity of children for the purpose of easing the burden on the guardians without any clear benefit to the children themselves (Ouellette, 2009). Critics also argue that there remains a paucity of data about the efficacy and side effects of

GAT in this population, without which its use amounts to an experimental medical procedure on disabled children who cannot consent (Brosco & Feudtner, 2006). Follow-ups with healthy women who were treated for tall stature as adolescents revealed no significant long-term side effects from GAT. However, there is a known risk for short-term pain and thrombosis, and any additional risks of treating at a younger age are unknown (Pyett et al., 2005). Though GAT proponents argue that there may be benefit to overall health, quality of life, and length living with guardians at home, ongoing knowledge gaps contribute to the controversy surrounding GAT. Similar concerns have arisen in debate about other interventions intended to ease care and increase quality of life for profoundly disabled children, such as sterilization, breast bud removal, and restricting weight to the low end of healthy through diet (Cureton & Silvers, 2017; Diekema & Frost, 2010). These interventions have a longer history of study and research than GAT, and GAT's use is complicated by the fact that sometimes interventions such as sterilization and breast bud removal are implemented in conjunction with growth attenuation.

GAT in the medical community

Currently, there are no nationally accepted clinical guidelines that outline the process by which medical professionals should discuss GAT with guardians, in which cases GAT is appropriate or inappropriate, and how treatment should progress. Furthermore, professional societies such as the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, and the American College of Medical Genetics and Genomics have demurred from publishing position statements. Clinicians continue to field questions and requests for GAT without guidance, and it is likely that these

discussions will become more frequent as GAT becomes more well-known to both guardians and clinicians.

In a survey of 284 American pediatric endocrinologists, approximately one in three respondents had been asked about GAT by parents of children with profound physical and cognitive disability, and approximately one in ten respondents had prescribed GAT (Pollock et al., 2015). There have been no formal surveys of American pediatricians, endocrinologists, geneticists, or genetic counselors that assess attitudes toward GAT and how those attitudes affect the ways in which medical professionals discuss, prescribe, and facilitate the treatment.

Independent commentaries by American clinicians and research from outside the United States provide some insight into the attitudes of medical professionals toward GAT. Some pediatricians have recommended that a discussion of GAT be initiated by the child's practitioner as anticipatory guidance for one of many treatments that some guardians may wish to consider (Allen et al., 2009; Wrigley et al., 2017). Other medical professionals have made statements decrying GAT as an inappropriate and unethical therapy for children with severe physical and cognitive disabilities (Tan & Brassington, 2017). In one study, approximately the same number of respondents believed that GAT was an inappropriate therapy for children with profound physical and cognitive disabilities as those who felt that GAT should be offered to all guardians of children with those disabilities (Wrigley et al., 2017).

Due to the starkly contrasting attitudes toward GAT, developing a comprehensive position statement or clinical guideline proves difficult. In 2010, a report was published of a 20-person committee formed to deliberate the ethical and policy considerations

associated with GAT (Wilfond et al.). This diverse group of professionals included experts in medicine, law, bioethics, and philosophy, as well as individuals and family members of individuals affected by significant disabilities. Ultimately, no consensus was made, but instead a "moral compromise": GAT is acceptable in some circumstances, but should be preempted with a structured decision-making process, meeting set eligibility criteria, and the involvement of an ethics committee. The format for these processes was not specified, but a preliminary guideline for eligibility criteria was suggested: appropriate candidates would be both non-ambulatory and non-communicative and their condition presumed to be permanent. These suggested guidelines were not satisfactory to all members of the working group, but generally align with guidelines for similarly controversial treatment such as sterilization of minors with profound disability (Committee on Bioethics, 1999; Paransky & Zurawin, 2003). Whether genetic counselors are aware of the results of this working group or if their practice is influenced by it remains unknown.

Genetic counselors and GAT

As genetic testing technologies advance - particularly whole exome sequencing – it is likely that geneticists and genetic counselors who disclose diagnostic and prognostic information to guardians will begin to face questions about GAT more often (Kuperberg et al., 2016). Genetic counselors play an important role for families affected by disability, since they see the same client annually or more frequently, participate in care coordination, and serve as a bridge between families and their medical team. A genetic professional's attitude toward and mode of addressing the option of GAT may influence decision-making process for the options available to guardians and their children.

Genetic counselors have unique education about the decision-making and adaptation process for families affected by disability. They frequently serve as care coordinators and patient advocates and may have unique contributions to the ethics discussion surrounding GAT. Understanding how genetic counselors view GAT will provide a clearer picture of how these conversations are conducted in the pediatric genetics setting.

Conceptual Frameworks: The Four Topics and the Zone of Parental Discretion

Four principles of biomedical ethics underlie ethical decision making in medicine: beneficence, non-maleficence, justice, and autonomy (Beauchamp, 2013). Based on these principles, Schumann and Alfandre developed the Four Topics approach to clinical decision making (2008). This approach encourages clinicians to approach ethical issues by developing four topics that can be broken down into specific questions that can be individualized to each case (See Figure 2).

Topic	Principles	Sample Questions	Additional GAT Questions
Medical Indications	Beneficence Non-maleficence	• What is the diagnosis and prognosis? • What are the goals of treatment? • What are the probabilities of success? • What are the plans in case of therapeutic failure?	• How severe are the child's disabilities? • To what degree might adult height be reduced? • What are possible side effects, and what is the likelihood of those side effects?
Quality of Life	Beneficence Non-maleficence Autonomy	• What physical, mental, social deficits is the patient likely to experience from the treatment? • What are the prospects, with or without treatment, for a return to normal life? • Is the patient's present or future condition such that their continued life might be judged as undesirable? • Are there biases that might prejudice the provider's evaluation of quality of life?	• How might the child's life and/or care be affected by their expected adult height? • How might the child's life and/or care be affected by GAT treatment? • Is there a plan in place for care if the family forgoes treatment?
Contextual Features	Justice	• Are there family issues that might influence treatment options? • Are there religious or cultural factors? • Are there problems of allocation of resources? • How does the law affect treatment decisions?	• How have the guardians talked about the use of GAT? What are their motivations? • What resources are available to the guardians to facilitate care? • Is clinical research a provider motivation for supporting GAT?
Patient Preferences	Autonomy	• Is the patient mentally capable and legally competent? • Has the patient been informed of benefits and risks? • Has the patient expressed prior preferences (eg, advance directives)?	• How are the child's guardians managing the decision-making process? • To what extent are the guardians incorporating the child's needs into the decision-making process? • Are the child's guardians making the decision without undue outside pressure?

Figure 2. The Four Topics approach to ethical decision making in medicine.

Even after addressing all four topics, clinicians may disagree about the weight placed on the values captured by the questions. The ultimate decision about whether to initiate GAT will involve a team including not only the genetic counselor and guardians, but also a geneticist, endocrinologist, and ethics committee.

The Zone of Parental Discretion (Gillam, 2016) is a tool recently developed to help such teams simplify decisions about when to deny the medical requests of guardians. Since determining the course that would be in the child's' "best interest" is both nebulous and personal, Gillam asserts that clinicians should strive only to determine whether the course desired by guardians would be harmful to the child. "Harm" is defined as a "serious setback of interests," including components of well-being such as continued life, freedom from pain, relationships with others, and experience of happiness. The Zone of Parental Discretion acknowledges that at times the options available to a child and their family may all be sub-par, but any decision that does not harm the child – even if it is not considered the "best" course of action by clinicians – is permissible. This tool leaves room for interpretation as to the meaning of "harm," and "serious", however, so clinicians using the Zone of Parental Discretion may come to different conclusions about whether GAT is appropriate for a child.

Significance

Because there are no national guidelines for addressing requests for GAT, clinicians may refer or deny referrals for GAT based on the dictates of their own moral frameworks. It remains unclear, however, how genetic counselors conceptualize the ethics of GAT, if there is pressure from their field or institutions to support or reject GAT, or if they even view the discussion of GAT for children with profound disability as an ethically distressing

event. Given genetic counselors' role as advocates, care-coordinators, and facilitators of the decision-making process, it is important to clarify their roles and needs as discussions of GAT for children with profound disability evolve.

METHODS

Participants

The target population for this study was pediatric genetic counselors with at least one year of experience. This population was chosen to capture the current understanding of and experience with GAT by those who may facilitate a referral, and to get a better understanding of the frequency with which this topic is discussed in pediatric genetic counseling sessions. We excluded genetic counselors new to the pediatric field to assure that respondents have had extensive experience working with guardians who have the concerns one might consider when thinking about GAT, such as quality of life and long-term care.

Instrumentation and Procedures

An electronic survey was developed using Qualtrics and was distributed to members of the National Society of Genetic Counselors (NSGC) via the NSGC email listserv. All participants were asked to share demographic information, their familiarity with GAT ("Are you familiar enough with GAT that you could describe its use to a colleague?"), and where they had heard of the intervention. The survey included a brief explanation of GAT for the participants to read, which included the primary arguments for and against its use. Respondents were then asked to share whether they personally support the use of GAT for children with profound disability, and to rate the extent to which the major arguments for and against GAT played a role in their opinion toward it. Semantic differential questions asked participants to rate GAT on the classical ethical tenants (beneficence, non-maleficence, autonomy, and justice) as well as its potential to

improve quality of life for child and guardian. A 5-point Likert scale was used to collect responses regarding genetic counselors' beliefs about how GAT would be addressed by them in clinical practice, as well as how they believe it should be addressed as a field. Respondents were asked if they had discussed GAT with a guardian in their clinical practice; respondents with experience were asked to elaborate on the content of that counseling, including the age and indication of the child, who initiated the conversation about GAT, and if a final decision was made about whether to pursue GAT. Respondents were also asked about their experience and attitude toward other controversial interventions considered in the pediatric setting: sterilization, breast bud removal, and diet restriction to maintain low weight. Finally, participants were asked about the perceived utility of a hypothetical guideline or position statement regarding how to counsel about controversial interventions. Open-ended, text-entry questions throughout gave participants the opportunity to elaborate on their answers. Respondents were offered the opportunity to elaborate on multiple choice questions such as their support or opposition to GAT and the other interventions and to elaborate on their interest in a guideline or position statement. The portion of the survey detailing personal experience with counseling for GAT included a text box to add any additional information that was important to their counseling.

Survey respondents who reported experience considering GAT for a child with profound disabilities were invited to participate in a semi-structured telephone interview about the content of the counseling involved, how their perception of GAT has changed overtime, and under what circumstances GAT is acceptable to them. Participants were also asked more broadly about how they decide whether to support or counsel against a

guardian's choice for a child, and what would be useful to include in guidelines regarding controversial interventions such as GAT, sterilization, breast bud removal, and diet restriction. Additional genetic counselors with experience considering GAT for a patient were recruited for an interview with follow-up emails through the NSGC listserv as well as flyers distributed at genetics conferences.

Data Analysis

Survey

Survey data were downloaded from Qualtrics and analyzed using Excel 2016 and R Studio with R 3.4.3. Variables were subjected to univariate, descriptive analysis to calculate ranges, means, standard deviations, and frequencies. Due to the sample size, survey analysis was exploratory and descriptive in nature. A total of 54 text responses were reviewed for recurring themes and were able to be coded using the codes developed during the interview analysis.

Interviews

Immediately post-interview, KA recorded her initial impressions of the major themes and notes for analysis. Major themes and analytic notes included the participant's overall tone and attitude toward GAT, recurring comments made by the participant, and any statements which concisely captured their responses to the interview questions. Interviews were transcribed verbatim by Production Transcripts and checked for accuracy by KA. Transcripts of interviews were analyzed in MAXQDA using thematic analysis, which allows for the identification of common themes between transcripts. In accordance with the reliability and validity practices set forth by Morse and colleagues, the collection and analysis of data occurred concurrently, and creating the codebook was an iterative

process that continued throughout the interview and analysis process, with multiple rounds of coding as new concepts emerged (Morse, 1997; Morse et al., 2002). KA met with JO three times over the course of the analysis to review the interview and analysis process and resolve analytic challenges.

Codes were developed inductively and deductively. Some codes were created based directly on questions in the interview guide. For example, KA asked all participants to describe a scenario in which GAT might be an appropriate intervention for a child. The code "When GAT is Appropriate" was created, as well as sub-codes to capture the responses given, such as "If Research-Backed" and "Only if Non-Ambulatory." A code was created to capture the concept of the Zone of Parental Discretion, which was elicited with the question "How do you draw the line in what you would support a parent choosing on behalf of their child?" and follow-up questions such as "What characteristics of a child or family do you consider when deciding for whom an intervention is appropriate?" and "What characteristics of an intervention make it appropriate or inappropriate for a parent to choose on behalf of their child?" Novel codes were identified over the course of the interview based on participant-initiated discussion independent of questions specifically directed by the interview guide. For example, when participants described aspects of a pediatric appointment which they believe are more appropriately addressed by a physician than a genetic counselor, such as medication recommendations or even GAT itself, a code was created called "Outside Scope of Practice."

After all codes were created and all coding iterations were complete, existing codes were organized into the Four Topics themes (Medical Indications, Quality of Life, Contextual Features, and Patient Preferences). Codes and coded segments concerning how

the participant perceives GAT and its utility were grouped under their appropriate Four Topics theme. For example, under “Medical Indications,” codes and coded segments were listed in which the participant described the medical context in which they feel GAT is appropriate, and how medical indications may play a role in the development of guidelines.

RESULTS

Survey Demographics

A total of 91 genetic counselors responded to the survey; 62 were included in analysis because they both met inclusion criteria and completed questions beyond the demographic portion. Demographic characteristics are presented in Table 1. Respondents were mostly women (90.3%) and white (95%), with one participant identifying as American Indian or Native Alaskan and two identifying as Asian. Although lacking representation from participants identifying as black/African American or as native Hawaiian/Pacific Islander and Hispanic or Latino/a, these demographics mirror trends identified through the National Society of Genetic Counselors' Professional Status Survey (PSS). The PSS revealed that responding genetic counselors were 95% women and 92% white, with 1% identifying as black or African American, less than 1% identifying as Hawaiian or Pacific Islander, and 2% identifying as Hispanic or Latino/a (2018). Over 85% of respondents were under the age of 40, compared to 70% in the PSS, and over half of respondents had 1-3 years of experience as a genetic counselor. Geographical representation mirrored the responses from the PSS for Regions 1-3, but region 4 was over-represented (45.2% compared to 28% in the PSS) and Regions 5 and 6 were under-represented (6.5% and 9.7% compared to 13% and 19% in the PSS).

Table 1. Participant demographics

Characteristic	Number (%)
Gender	
Woman	56 (90.3)
Man	5 (8.1)
Other	1 (1.6)
Race	
White	59 (95)
American Indian or Alaska Native	1 (1.6)
Asian	2 (3.2)
Black or African American	0
Native Hawaiian or Pacific Islander	0
Spanish or Latino/a	
No	62 (100%)
Yes	0
Age	
20-29	32 (51.6)
30-39	21 (33.9)
40-49	3 (4.8)
50-59	6 (9.7)
Years of Genetic Counseling Experience	
1-3	35 (56.5)
4-8	12 (19.4)
9-15	10 (16.1)
16-20	1 (1.6)
21-30	3 (4.8)
31-40	1 (1.6)
Years of Pediatric Genetic Counseling Experience	
1-3	37 (59.7)
4-8	13 (21.0)
9-15	9 (14.5)
16-20	1 (1.6)
21-30	2 (3.2)
NSGC Region	
Region 1 (CT, MA, ME, NH, RI, VT, CN, Maritime Provinces)	4 (6.5)
Region 2 (DC, DE, MD, NJ, NY, PA, VA, WV, PR, VI, Quebec)	13 (21.0)
Region 3 (AL, FL, GA, KY, LA, MS, NC, SC, TN)	7 (11.3)
Region 4 (AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, SD, WI, Ontario)	28 (45.2)
Region 5 (AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Sask)	4 (6.5)
Region 6 (AK, CA, HI, ID, NV, OR, WA, British Columbia)	6 (9.7)

Knowledge of GAT

When asked if they are familiar enough with GAT to describe its use to a colleague, 67.7% of respondents (42) answered 'No.' Participants who were familiar with

GAT were asked to select all the places from which they learned about the intervention (figure 3). Sources of information varied widely, with 4 respondents not remembering at least once source of information about GAT and an additional 8 not remembering where any of their knowledge of GAT came from. One respondent selected 'other' as their source of GAT knowledge, and in a text response clarified that they had heard of GAT in an undergraduate course.

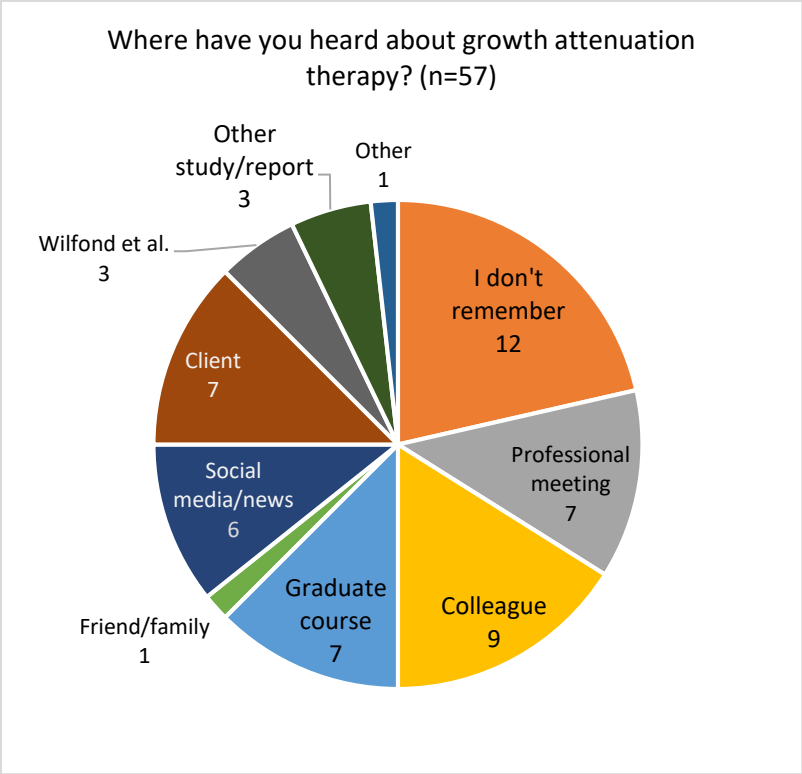

Figure 3. Sources of information about GAT. "Professional meeting" included ethics committee, case conference, educational sessions, etc.

Personal Attitude Toward Controversial Interventions

Twenty-four respondents (38.7%) reported that they personally support GAT for use with profoundly disabled pediatric patients, while 16% opposed its use and 17% reported that they "cannot not say – I do not lean one way or the other." Growth attenuation therapy received the most support, followed by sterilization, diet restriction,

and finally breast bud removal, which most of the respondents (69.6%) opposed (figure 4).

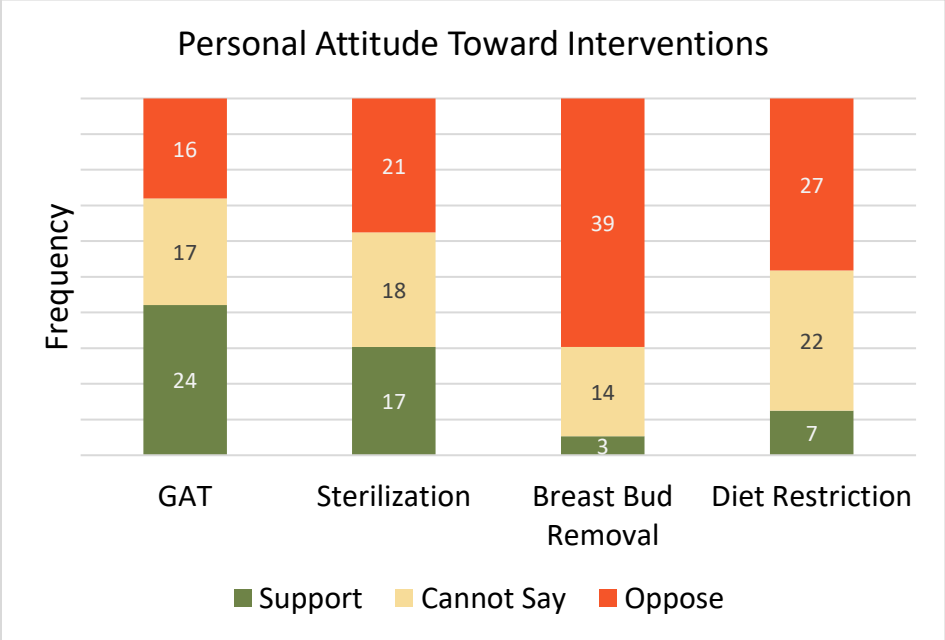

Figure 4. Genetic counselors' attitudes toward the interventions included in the study. The n for GAT was 57, while the n values for sterilization, breast bud removal, and diet restriction were 56. Sterilization was specified as "Sterilization (for children with otherwise healthy reproductive systems)," breast bud removal was presented as "Breast bud removal (for children with no health concerns related to breasts)" and diet restricted was, "Restricting diet to maintain weight on the low end of healthy."

Understanding Support and Opposition Toward GAT

Genetic counselors who support GAT weighed the arguments to support and oppose the intervention differently from genetic counselors who oppose GAT (Figure 5). For genetic counselors who support GAT, the primary reasons are that it helps guardians lift, move, and care for their child in other ways, it has the potential to increase family quality of life, and it makes long-term home care more feasible. For counselors who oppose GAT, the primary reasons are that the side effects are poorly understood, it infantilizes children into adulthood, and children cannot consent/assent. Supporting genetic counselors were less likely to take infantilization or side effects into account

when forming their attitude toward GAT, and opposing genetic counselors were less likely to take into account the potential quality-of-life benefits such as longer home-care and involvement in vacations.

Eleven text responses elaborated on respondents' stance toward GAT. Five text responses from genetic counselors who support GAT emphasized that it should be considered on a case-by-case basis, and that the decision to pursue GAT is a personal one. Some went on to say that they would not initiate conversations about GAT until the proposed benefits are confirmed:

"I answered that I "lean toward supporting" GAT, but it is not something that I would provide as an option to my families at this point unless the family mentioned it first. I think there should be a great deal more research regarding side effects and QoL [quality of life] before it could be considered a standard offering in these types of cases."

Genetic counselors who oppose GAT reinforced their disbelief in the proposed benefit for the child and emphasized that the suggested benefit for the caretakers is not sufficient for implementing the intervention:

"I believe medical interventions should only be used to improve the health and quality of life. I find medical interventions for the sole purpose of easing a caretaker's job unethical."

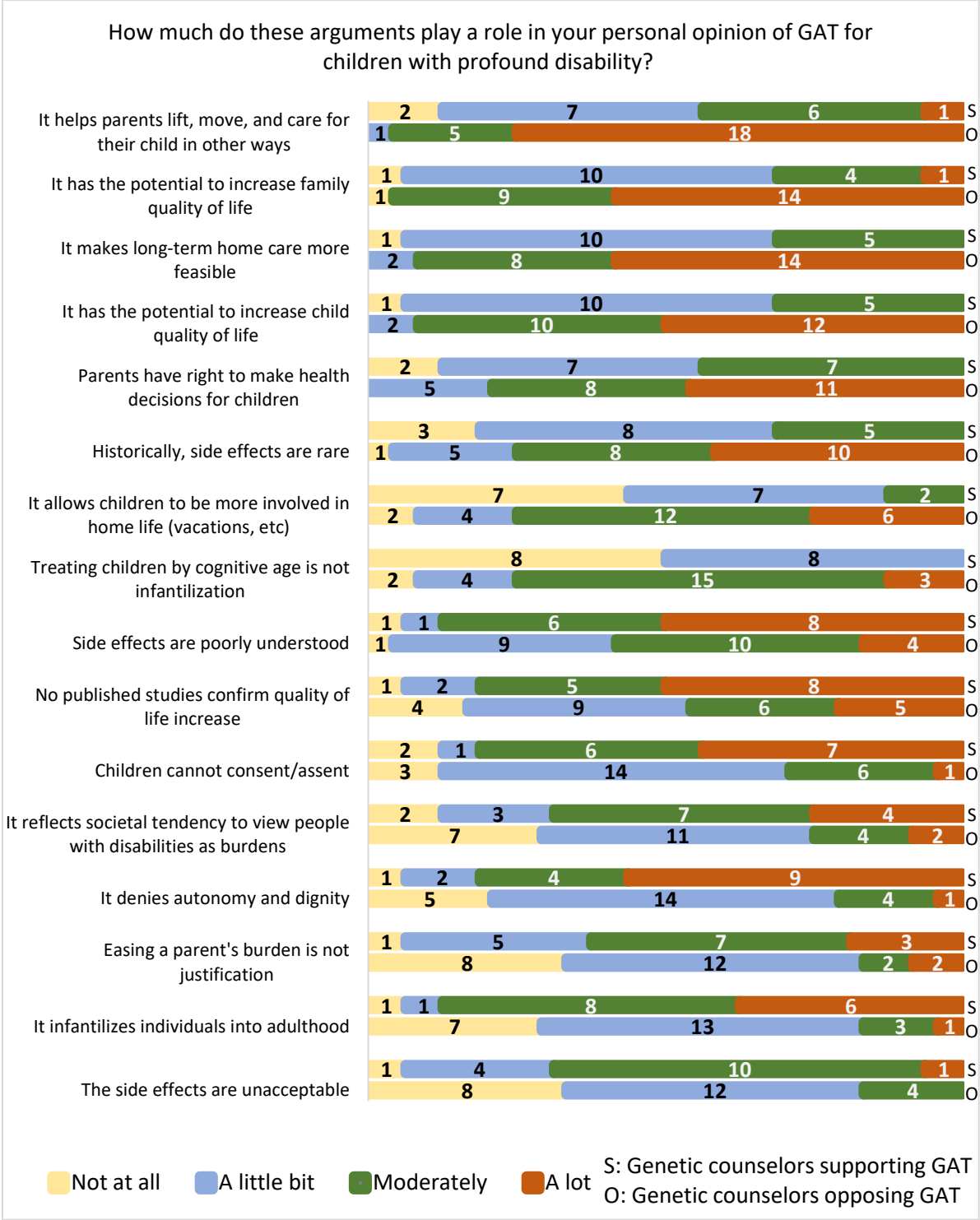

Figure 5. Arguments to support or oppose GAT, ranked by genetic counselors supporting GAT(S) and opposing GAT (O). Supporter n=24; Opposer n=16.

Semantic differential questions assessed genetic counselors' beliefs regarding how GAT interacts with the four basic ethical principles as well as the degree to which it impacts quality of life for guardians and affected children (figure 6). Responses from genetic counselors in all three attitude groups (supporting, cannot say, opposing) followed the same gross pattern except that supporting and opposing groups diverged in their belief about GAT's beneficence and converged in their belief about its maleficence. Other notable differences in beliefs include that genetic counselors opposing GAT identified it as an intervention which decreases patient quality of life and is unjust, while those supporting GAT believe that it increases patient quality of life and is just. All groups reported that GAT increases parent quality of life, denies patient autonomy, and supports parent autonomy. In general, genetic counselors opposing GAT ranked the intervention lowest on these ethics measures and genetic counselors supporting GAT ranked it highest, with the cannot say/neutral group rating the intervention in between the ratings of the other two groups. Three exceptions were the ratings for GAT's effect on parent quality of life and patient autonomy, for which the "cannot say/neutral" group aligned more closely with genetic counselors supporting GAT, and the rating for GAT's effect on parent autonomy, for which the "cannot say/neutral" group aligned more closely with genetic counselors opposing GAT.

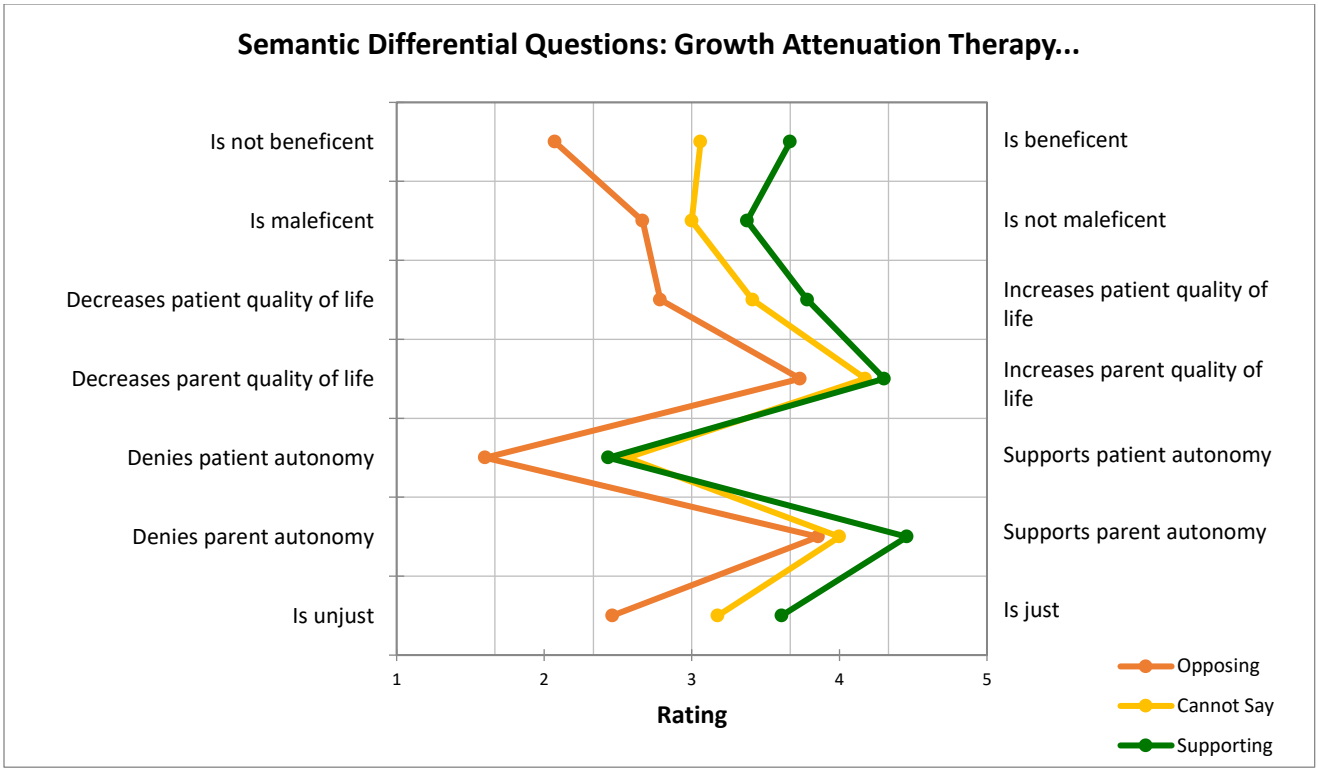

Figure 6. Semantic differential responses from genetic counselors opposing GAT (n=16), supporting GAT (n=24), and those who felt neutral or could not say if they support or oppose GAT (n=17).

Clinical Guidelines

Table 2 summarizes respondents' interest in a guideline or position statement from NSGC about how to counsel for controversial interventions. Most respondents felt that a guideline or position statement would be beneficial and would reference a guideline or position statement to inform their clinical care. Nine respondents elaborated on their stance in text responses, all of whom either supported guidelines or reported that their utility would depend on their content. Respondents suggested that useful guidance would include current published data on GAT's risks and benefits as well as guidance surrounding psychosocial counseling for guardians who are considering GAT for their child. Participants who were unsure about the utility of a guideline or position statement emphasized the limited role that genetic counselors have when it comes to medical care decisions. These responses suggest a divide in both the perceived role of NSGC

guidelines and position statements and the perceived role of genetic counselors themselves. Genetic counselors who are interested in a guidance from NSGC highlight the role of genetic counselors in therapeutic counseling of guardians who are in a situation which may lead them to consider shortening the adult height of their child and are interested in tools to help them better engage families in thinking about this option in relation to other options. Genetic counselors who see little utility in a guideline or position statement are those who highlight the medical aspect of GAT as an intervention and do not believe genetic counselors could use a guideline given the field's limited scope in counseling for the genetic components of care. It may be that there is overlap between these two groups which is not captured by the text responses provided.

Table 2. Utility of guidelines regarding controversial interventions

	Do you feel that the NSGC would benefit from drafting guidelines or position statements about how to counsel for topics such as GAT, sterilization, breast bud removal, etc.?	Would you refer to an NSGC guidelines or position statements about how to counsel for these practices if they were available?
Yes	39	45
Not sure	9	6
No	5	2
It depends	3	3

GAT in Clinical Practice

Eight genetic counselors reported discussing GAT with guardians, with a total of 13 separate instances. Table 3 summarizes the indications and referral decisions for the reported cases. For one session, the genetic counselor did not report the indication/symptoms of the child involved. In most sessions, the option of GAT was brought up by a parent or guardian. The exceptions were three sessions in which GAT was first brought up by either an endocrinologist or geneticist. Most cases, including

those for which a physician initiated the GAT discussion, involved children with profound intellectual and physical disability. Guardians were rarely referred to an endocrinologist to further discuss GAT, and in only one case did the genetic counselor report that the guardian(s) chose to pursue the intervention. In no cases was an ethics committee involved in decision-making. Of the genetic counselors who had discussions about GAT with caretakers, nine reported being supportive of GAT and five reported an ambivalent stance.

Genetic counselors elaborated on their responses in free-text answers. Genetic counselors reported that these discussions were often preliminary, information-gathering discussions that guardians sometimes planned to consider in addition to separate discussions with other clinicians. These discussions were often complicated by the medical presentation of the patient and the lack of research regarding GAT's risks and benefits. Without knowing how the effects of GAT could interact with the symptoms and risks of the child's condition, teams were not prepared to advise families about the utility of the intervention.

Table 3. Summary of GAT counseling sessions of eight genetic counselors

Indication	Number of times discussed	Number referred to endocrinologist to further discuss option	Number of sessions after which GAT was pursued	Number of sessions after which GAT was declined	Number of sessions after which no decision was made about GAT
Profound intellectual and physical disability	6	3	0	1	5
Profound intellectual disability	2	0	1	0	1
Condition with variable intellectual and physical disability	2	0	0	1	1
Overgrowth disorder	2	1	0	0	2

Fifty-six respondents answered questions regarding their attitude and beliefs surrounding how GAT is addressed in the clinical setting (Table 4). Genetic counselors were split on whether GAT is appropriate for children with profound disability, as well as their level of discomfort counseling families about the intervention given the ethical concerns. Nearly all genetic counselors reported some level of discomfort counseling families about GAT due to their limited knowledge about the intervention. A minority of respondents felt that GAT should be offered to all guardians of children with profound disability. Most genetic counselors were at a minimum willing to talk to families about the option of GAT, but five reported that it is not something they would discuss, no matter the circumstances. Most genetic counselors would feel it important to make guardians aware of the ethical concerns surrounding GAT. Regarding the final decision about pursuing GAT, most respondents were supportive of a child's guardians making the final decision about whether to pursue, followed by an ethics committee. Genetic

counselors were least supportive of the medical team making the final decision about whether to pursue GAT.

Table 4. Opinion on GAT practice (all respondents)

Practice Statements	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
GAT for children with profound disability is not appropriate.	8 (14.3%)	19 (33.9%)	18 (32.1%)	8 (14.3%)	3 (5.4%)
I would feel discomfort counseling a family about the option of GAT due to the ethical concerns.	5 (8.9%)	14 (25.0%)	11 (19.6%)	19 (33.9%)	7 (12.5%)
I would feel discomfort counseling a family about the option of GAT due to my limited knowledge about GAT.	0 (0.0%)	4 (7.1%)	6 (10.7%)	20 (35.7%)	26 (46.4%)
I would not discuss the option of GAT with a family, no matter the circumstances.	22 (39.3%)	22 (39.3%)	7 (12.5%)	1 (1.8%)	4 (7.1%)
If a guardian brought up the option of GAT in a session, I would express to them the ethical concerns associated with its use.	2 (3.6%)	5 (8.9%)	6 (10.7%)	29 (51.8%)	14 (25.0%)
GAT should be routinely offered to guardians of children with profound disability, not just discussed when raised by a guardian.	9 (16.1%)	12 (21.4%)	23 (41.1%)	9 (16.1%)	3 (5.4%)
The final decision on whether GAT is appropriate for a child with profound disability should be made by the child's medical team.	7 (12.5%)	11 (19.6%)	22 (39.3%)	14 (25.0%)	2 (3.6%)
The final decision on whether GAT is appropriate for a child with profound disability should be made by an ethics committee.	4 (7.1%)	8 (14.3%)	20 (35.7%)	18 (32.1%)	6 (10.7%)
The final decision on whether GAT is appropriate for a child with profound disability should be made by the child's parents/guardians.	1 (1.8%)	6 (10.7%)	18 (32.1%)	26 (46.4%)	5 (8.9%)

Interview Participants

Between survey respondents and participants recruited at genetics conferences, eight genetic counselors with experience considering GAT for a child were interviewed.

Six of the genetic counselors had first heard of GAT from a patient's guardian, one had first heard about it in the news, and one had it first heard about it when it was brought up in an ethics committee meeting. All interviewees reported that when GAT was brought up in a clinical session, it was by guardians who were in the initial stages of exploring the intervention as an option, and to their knowledge, none of the guardians pursued GAT after speaking to the genetic counselor and their team. Indications represented included profound intellectual and physical disability, an overgrowth syndrome, and various conditions whose presentation differs between individuals, designated "variable" for the purposes of this study.

Initial Reactions and Changing Perspectives

Interviewees shared that when GAT was first brought up, they were surprised by the option and felt they had to do additional research to understand it and address it with families. Most felt unprepared to engage guardians in a discussion about GAT. Both supportive and oppositional attitudes were represented in initial reactions.

"I actually felt like for practical reasons I could be supportive of the therapy, just because I know how difficult it was for these families and caring for all the activities of daily living for their living. And I knew they were going to get bigger and the parents were going to get older and it was just going to become more and more challenging to manage this stuff over time." (Genetic counselor 8; Indication: profound intellectual and physical disability)

"I think (I felt) surprise, initially, but also recognition of I suppose how it would be helpful. But I tend to look at it as, "Well, there are lots of things that could be helpful but still aren't right to do" (Genetic counselor 7; Indication: variable intellectual and physical disability)

For some genetic counselors, their attitude toward GAT has shifted over time as they did more research on the topic. Shifts toward a more positive perception of GAT and a more negative perception of GAT were both represented. Some who initially appreciated the proposed benefits of GAT became more ambivalent or negative toward the intervention after learning about the lack of research supporting its benefits or concerns regarding the children's best interests and autonomy.

"When I first saw it before actually reading into it and spending some time to think about it I'm like oh, this could be potentially very beneficial…But my perspective definitely has changed a little bit since my first Google search about it. I am definitely more against than for it…who is our patient is the big question that kind of opened my eyes a little bit." (Genetic counselor 1; Indication: variable intellectual disability)

Participants whose attitudes grew more positive over time reported feeling more ambivalent about the intervention, and that its appropriateness depends on the circumstances of the child and family.

"Initially, I kind of questioned it, and it took me a little bit to kind of process exactly how I felt about it just because I think as genetic counselors we have a tendency to think not

just about the practical side of therapies but the ethical side as well and how it's going to impact the patient's well-being…now I think it really comes down to getting to know the family and in particular the patient and seeing kind of where they're at depending on where they're at developmentally and where their physical abilities are and exactly what the struggles are with their guardians as far as would this really be the best thing for the well-being of the patient." (Genetic counselor 3; Indication: variable intellectual and physical disability)

These genetic counselors reacted differently toward discussing GAT the first time they heard it than they would in the future, needing time to process and reflect on what GAT means and its implications for their patients.

Addressing GAT in a Session

None of the genetic counselors interviewed felt comfortable coordinating a referral to an endocrinologist. Reasons for this included an opposition to GAT itself, feeling that discussing GAT was outside a genetic counselor's purview, and the specific patient's indication (e.g., child was older than recommended for GAT, child had only minor intellectual disability). There were three primary responses genetic counselors and their teams gave to guardians considering GAT for their child: defer to a physician, verbally oppose, or offer psychosocial counseling.

Some genetic counselors shared that they often immediately defer questions about medical management to their clinician.

"(I) defer to my medical team. In the moment, I'm not sure if I would get into it, but it's pretty common for me to get questions about medical management that I just bounce right back to the medical team because I don't deal with any of that. I get a little bit sheltered in my genetic counseling role." (Genetic counselor 7; Indication: variable intellectual and physical disability)

Typically with input from a physician, some teams declined to discuss GAT due to the ethical concerns.

"(The doctor) was very much like, "It's not something that I can prescribe." He's like, "I don't recommend it, especially for (this indication), just all the ethical concerns around it… I wasn't quite as blunt…I directed it more of like this really wouldn't benefit the patient. It's not going to prevent the symptoms." (Genetic counselor 1; Indication: Variable intellectual disability)

Some of the genetic counselors who opposed GAT emphasized that it is not a treatment for the symptoms of physical or intellectual disability. This fact is implied by the goals of the intervention and has been raised indirectly by clinicians who argue that the intervention benefits guardians alone, but these genetic counselors presented a different argument. These genetic counselors were open to the possibility that there could be a yet unconfirmed quality of life benefit to the intervention but concentrated on the medical aspects of the child's condition and found GAT inappropriate unless it could address clinically identified symptoms that a pediatric clinic is structured to treat.

"We agreed that other people do this and we aren't going to say that anybody is horrible for doing this, but it is not treating the disorder that we are there to treat." (Genetic counselor 7; Indication: variable intellectual and physical disability)

Although most genetic counselors reported that their team would simply decline to discuss referral for an intervention to which they are opposed, one genetic counselor shared that her team will refer out to other institutions for interventions that are unavailable or not prescribed at their own clinic. This was described as a norm of her institution to help clients access the interventions they seek, even if those interventions are not supported by the team at her institution.

"…If another hospital has a different opinion on the ethics of the case and they're aligned with the family, then we will do everything we can to help get them to that organization to have that discussion internally." (Genetic counselor 5; Indication: Profound intellectual and physical disability)

Interviewees also shared that although they felt unprepared or unwilling to talk about GAT as a feasible option at the time of the session, it is important to them to understand the guardians' perspective and household struggles that led to considering GAT as an option, and to provide support as they face the future of caring for their child. Genetic counselors reasserted that within their teams, medical management questions are typically deferred to a physician, and the limited information surrounding GAT

compounds genetic counselors' reluctance to delve deeply into its utility for a child. However, their training and experience working with clients facing difficult medical management decisions means that GCs are well-positioned to help clients considering GAT to develop further insights into their own values and resources.

"I think I feel more comfortable kind of being supportive of them and trying to help them with this, just because I have seen a lot of patients and I know what the daily challenges are for these families…Also, I'm a parent. Maybe that helps, too. I can really relate to how difficult that would be to change the diaper of a 200-pound guy, you know what I mean?" (Genetic counselor 8; Indication: profound intellectual and physical disability)

These genetic counselors also emphasized welcoming further discussion about why the client is considering GAT, rather than immediately deferring to a physician or declining to discuss the option. They found it important to understand the context in which a client considers the option and to create a space in which clients taking on the important role of caring for an affected child can share their story and feel heard and respected.

"I believe we have nothing to gain from closing doors on options that parents bring to us. I don't think that means we then need to offer the service, but we should at least be open to having the discussion and hearing what's led them to wish to pursue that as an option…We can try to make sure that to the best of our ability our patients feel heard and that we're not just disregarding the experience that they bring to the table in caring for

their child, because they know more about that child than anyone in the health care team and we should respect that experience." (Genetic counselor 5; Indication: variable intellectual and physical disability)

Although none of the interviewed genetic counselors had teams that have referred clients to GAT services, these participants counseled with a less directive stance in order to create an environment in which clients felt comfortable to share their worries and obstacles and felt heard by the team.

Themes Within the Four Topics

Themes relating to the four topics arose in the interview when considering participants' attitudes toward GAT's utility and for whom it might be appropriate. Themes and subthemes are summarized below and presented with representative quotations in table 5.

Medical Indications

When asked for which indications GAT might be appropriate, participants highlighted the nuance to each situation and how an objective guideline for whom GAT is appropriate would be impossible to establish. Generally, participants agreed that GAT was inappropriate if the child's condition has the potential of improving, and that it was less appropriate if the child is ambulatory. Most participants supportive of GAT were inclined to accept the intervention in the context of a child with profound intellectual disability. Additionally, two genetic counselors shared their experience working with clients who have profound physical but no intellectual disability. Sometimes these clients express concerns about how their care might change as they and their caretakers age,

which led these genetic counselors to suggest that GAT may also be appropriate when the indication does not include intellectual disability.

Quality of Life

Participants who opposed GAT highlighted the unproven benefits to the family or child. Additionally, those participants who support the intervention emphasized that more research must be published to confirm the proposed benefits. Suggestions included interviews with parents who elect or decline GAT to understand their motivations and goals, longitudinal studies to monitor for side effects and benefits, and assessment of length of home-care for children whose diagnosis includes both profound disability and short stature as proxies for children who complete GAT.

Contextual Features

When participants chose to explore the psychosocial components affecting a guardian's decision to consider GAT, they typically thought about the child's indication in combination with the guardian's resources and support network. Some participants asserted that other strategies to relieve parenting stressors, such as access to home-care resources, should always be pursued first before considering GAT as an option.

Some genetic counselors also emphasized the importance of involving disability advocate groups in discussions of when GAT is appropriate. These genetic counselors asserted that the medical community would do well to understand the perspective of these advocates to try and address their concerns while working to understand for whom GAT is appropriate.

Patient Preferences

Most interviewees expressed continued concern that a child with a profound disability cannot express their care preferences or consent to GAT, and that the intervention undermines the child's autonomy. One genetic counselor emphasized that there is no way to know what medical advances will be developed in the future, and that protecting possible future autonomy is important despite any present indication. Genetic counselors questioned for whom the intervention was being pursued: children or their caregivers. For some of these genetic counselors, the decision to pursue GAT relied on understanding the context of the family situation to extrapolate what the child would want if they were able to express it. Other GCs supportive of GAT asserted that pursuing the intervention does not threaten the autonomy of the child because a child with a profound disability does not have autonomy to lose. Regarding the four topics, patient preferences overlap with medical indications, particularly in the case of children able to express concerns about their care.

Table 5. Four Topics themes, subthemes, and representative quotations

Theme	Subtheme	Quotations
Medical Indications	Difficulty establishing guidelines based on indication	"The more and more training that I've gotten in ethics, the more nuanced these issues become…where you might want to make strict guidelines based on (some cases), the next case comes along and throws another piece into the puzzle that complicates following a strict guideline." (Genetic counselor 4; profound intellectual and physical disability)
	Degree of disability	"If you have a condition where there is an expectation that a treatment may shift their capacity in the future…now you go to the arguments of protecting future autonomy" (Genetic counselor 1; variable intellectual disability)
		"It…would depend on the degree of independence, right? Maybe not necessarily the intellectual disability, but can they do activities of daily living…It's a practical question. Like, can they transfer, can they go to the bathroom, can they-- you know?" (Genetic counselor 8; profound intellectual and physical disability)
	Age cutoff	"Given their age (11-12), the expected effects of GAT weren't going to be significant anyway." (Genetic counselor 3; variable intellectual and physical disability)
Quality of Life	Unproven benefit	"…doing something with known side-effects without any evidence of benefit is not something that I recommend. I think it becomes very different if we have good evidence of a direct benefit to the patient…But lacking that, I think it's a lot harder sell." (Genetic counselor 6; profound physical disability)
	Further research	"They could…do comparable studies looking at conditions where children just naturally are smaller who have very significant limitations and need (help with) very basic care, compared to children who are larger and/or have kind of typical growth…and be able to use that as maybe a starting metric to see if there is any real benefit in having this offered." (Genetic counselor 4; profound intellectual and physical disability)
		"…it'd also be interesting to hear a collection of experiences, if things had gone through ethics committees, and the different decision-making that those ethics committees had gone through, and (if GAT was) ultimately being approved or not…how families felt about it, too, after doing it, if they decided it was ultimately a good idea or not. I think those would all be helpful things." (Genetic counselor 5; variable intellectual and physical disability)
Contextual Features	Indication's impact on context	"…the child had profound intellectual disabilities and in addition had severe seizure disorder, so would seize 20- 30 times per day…did not do any activities as daily living, relied on the family to do all of his care, the diapering and feeding and moving and transfers…" (Genetic counselor 8; profound intellectual and physical disability)
	Caregiver context	"This patient was so impaired and the mom was a single mom and having a hard time as she was getting older…It was just becoming more and more difficult for mom as she got older and as the child was growing to just move her around and take care of her." (Genetic counselor 8; profound intellectual and physical disability)
	Trying other solutions first	"(GAT could be appropriate) if it's a family where they just don't have the resources to make changes in their home to help with care." (Genetic counselor 3; variable intellectual and physical disability)

	Disability advocate involvement	"(GAT's proposed quality of life benefits) seem like something that would be a benefit to the child and then the adult. But the argument against and especially comments from people within the disability community certainly plays into the challenge of making sure that this is actually for the benefit of the child and not, you know, for the convenience of people caring for them." (Genetic counselor 4; profound intellectual and physical disability)
Patient Preferences	Who is the client?	"It may allow for the child to potentially receive better care from their parents…But, I guess, my biggest issue is what happens when…the parents aren't around anymore…are they more prone to be taken advantage of because of their size?...When they're older, who is it conveniencing?" (Genetic counselor 1; variable intellectual disability)
	Protecting autonomy	"Part of the argument in this is that these individuals will never have the capacity to make that decision for themselves due to the severity of their condition, but I think that would be an important consideration of maybe not now but in the future could their capacity change." (Genetic counselor 4; profound intellectual and physical disability)
	Preference if child could choose	"…While it might take autonomy away for some of these children, in the long run, keeping them with their families, or being able to keep them more mobile and able to go out and about with their families…is important, and I think probably what, if they were able to express their needs, potentially what they would prefer." (Genetic counselor 5; variable intellectual and physical disability)
	Profoundly disabled children lack autonomy	"I know there are ethical issues that come up with this, but to me the children unfortunately don't have a lot of autonomy, because they're so limited…they couldn't make a decision about that and so the parents are their surrogates in decision-making. So, I don't really even see a conflict between the patient's autonomy and the parents' autonomy in those such severe cases." (Genetic counselor 8; profound intellectual and physical disability)

Zone of Parental Discretion

Interviewees' perspective on where to draw the line in parental decision-making aligned closely with the concept of the Zone of Parental Discretion; participants all asserted that guardians should make the final decision about any medical option, except for in the case of "clear harm." All participants offered scenarios of clear harm or risk such as denying a child with a metabolic condition the diet that would prevent symptom development or pursuing a new and untested intervention without monitoring its effects. Many participants asserted that although a genetic counselor might invoke psychosocial counseling techniques to better understand and acknowledge a guardian's reasoning for pursuing a contraindicated intervention, non-directiveness should not be maintained in

these instances. Instead, genetic counselors should concertedly counsel against the option or involve appropriate authorities such as a social worker, child protective services, or an ethics committee.

"It should ultimately be the parents' call. But it comes back to is there any clear harm to the child, for making this decision? So in a situation where there is clear harm, then I think that's when it's appropriate that, you know, potentially you need to step in and alert social work, or alert an ethics committee, where there's something concerning going on in how this family's caring for their child." (Genetic counselor 6; Indication: profound physical disability)

Genetic counselors who compared GAT to sterilization viewed sterilization as more harmful, as it may be an invasive surgery and its benefits can be achieved through other means such as birth control. However, the perception of GAT's harm varied. Genetic counselors who opposed GAT shared that the potential side effects presented enough risk that GAT is inappropriate to them. However, when asked to elaborate, no interview participants were able to list specific side effects of GAT. They instead asserted that because there are no rigorous studies on side effects in this population, the risk for unknown side effects is reason to deny access to the intervention until clear benefits are established. Others perceived the risk of side effects to be low, and the potential benefit to be high enough to support GAT.

Guardians as Advocates and Researchers

A persistent theme among interviewees who were neutral toward or supported GAT was the concept of guardians acting as advocates and researchers to improve their child's care. They emphasized that guardians do not flippantly make medical decisions for their children and may consider GAT only after careful deliberation.

"The phrase 'therapy of last resort' kind of pops into my head repeatedly when I think about this. I think families who are considering some of these options are at a place where they are really searching for something that will make a meaningful difference for them. In my experience, this has not been a consideration that people have taken lightly at all." (Genetic counselor 2; Indication: overgrowth syndrome)

These genetic counselors also raised the historical significance of parents advocating for new treatments and interventions and the benefit that advocacy has provided the medical community and its patients.

"And so sometimes it's really the families that drive some innovation and push the envelope. Really this one, we were the first case report for (increasing the dose of a medication). That was the mom that was like, "I want to go up!" She really pushed us to go up on the dose. And there was no harm in it, and then it changed the whole field. So all the kids are getting it, and they're getting it younger now because these other families

pushed it." (Genetic counselor 8; Indication: profound intellectual and physical disability)

Participants also reemphasized the need of many guardians to feel respected and heard by their medical teams. Caregivers who feel ignored or misunderstood by their primary clinicians may seek interventions elsewhere, for better or worse.

"Many come with stories of, you know, we wanted this considered, or we had this concern and they felt like it wasn't given appropriate attention by their medical provider. A lot of things… now being offered as treatments were historically used and developed by parents because they felt like that need wasn't being met by the medical community." (Genetic counselor 5; Indication: profound intellectual and physical disability)

These genetic counselors held respect for guardians exploring medical options as a tenant of their counseling style and emphasized empathy and support for guardians during the parenting process, even in the context of trying to persuade a guardian against a choice involving clear harm.

Genetic Counselors' Role in Ethical Decision-Making

All genetic counselors interviewed highlighted ways in which genetic counselors offer expertise in discussions of ethical decision-making. Of primary significance were genetic counselors' psychosocial counseling skills, which allow them to explore the nuance of a family's circumstance and develop a holistic understanding of a patient and their guardians. Although genetic counselors frequently face unique circumstances and

questions about interventions such as GAT about which they know little, the psychotherapeutic training genetic counselors receive gives them tools to productively discuss these options and the clients' needs in an open and less medicalized way than a physician might.

"Genetics deals with a bunch of the weird situations. That is our bread and butter, is the unusual stuff, and honestly that's a lot of time where you find questionable things, is in the unusual cases, and so I think our comfort in that kind of space would be valuable. And I think that…having people who perhaps come from a more non-directive background might balance out some of the more directive MDs in the bunch. And I feel like we get a lot more training and experience with talking through things, and difficult topics, with patients than a lot of MDs have time for." (Genetic counselor 7; Indication: variable intellectual and physical disability)

These skills - and the additional time that genetic counselors have to spend with clients - offer clients an environment in which to feel heard and understood. Genetic counselors also act as a bridge between the client and their care team and so can make sure that all voices are considered as a decision is being made.

"…We're able to see kind of both perspectives usually-- there's the patient perspective and the physician-medical perspective-- I think differently than maybe the physicians do. And so we have such a unique opportunity…The physician probably doesn't have time to hear about the day-to-day of "We'll have to lift the child and then I have to diaper," and

all this stuff, right?…People that are in the kind of day-to-day care of the patients can really empathize more. And so that may help us really have a better perspective on these bioethical conflicts that come up." (Genetic counselor 8; Indication: profound intellectual and physical disability)

Suggestions for Guidelines

Beyond the additional research interviewees recommended to further understand the implications of GAT, participants made suggestions for what might be useful in a practice guideline developed for counseling about controversial interventions such as GAT. Some responses mirrored those from the survey, indicating that it would be most valuable to have recommendations on how to elicit a narrative to better understand the worries and goals of a guardian considering a controversial intervention and how to help them think through their options. Interviewees also recommended developing a toolkit to help genetic counselors think about and choose appropriate ethics resources when appropriate.

"(What would be useful is) different documents in regards to kind of ethical decision-making, different avenues or people you might be able to contact, to help with some of your decision-making. You know, different structures, maybe, that people go through with making some of these difficult decisions, or things like that. So I think more of a toolkit would be more appropriate than an actual position statement." (Genetic counselor 6; Indication: profound physical disability)

Most of the interviewees reported that decisions about how to counsel were typically made as a team, but the weight that each team member had in making decisions varied. One common suggestion for a guideline was a compendium of experiences making difficult clinical decisions and how teams might be structured to better meet clinical goals, as well as the resources used to meet those goals. Participants reported that having a mentor in ethics, such as an experienced genetic counselor or member of an ethics committee, was invaluable when facing complicated counseling cases. Genetic counselors recommended that a useful guideline would also offer suggestions to develop and structure a peer supervision group, which can serve as a resource for difficult or complex cases.

"(How to develop) a peer supervision group…Put in a plug for that. That's a great, great place to get the comments of your peers on difficult cases." (Genetic counselor 8; Indication: profound intellectual and physical disability)

For many of the GCs interviewed, these are skills which were honed and resources that were learned over the course of clinical practice, rather than in their graduate programs. It is useful to know how to counsel for difficult and poorly researched topics and to know where one can turn in difficult situations regardless of a genetic counselor's specialty or experience level., Having resources available to learn about these options would be especially useful given that they are not regularly included in graduate training.

Interviewees acknowledged that genetic counselors are not typically central to medical decision-making, and that a useful guideline for when it is appropriate to implement GAT would be best developed by or in collaboration with a larger clinical organization. Many suggested, however, that a guideline should include the recommendation to involve members of the team such as genetic counselors who can incorporate psychosocial counseling and the elicitation of values and goals to help guardians make decisions that align with their values.

"I think (the guideline should include) an emphasis on the role that genetic counselors can play…I frequently think that genetic counselors are in a position where they may be the only provider who talks about issue X and you could fill in the blanks there for a lot of things with a particular family and…I think we all received training on things like anticipatory guidance. I think this falls under that rubric, you know, discussing some of these again, options that may be controversial or where different families may make very different decisions depending on their own interpretation or conceptualization of the decision…I think that would be helpful." (Genetic counselor 2; Indication: overgrowth syndrome)

DISCUSSION

This research is the first to explore clinicians' practice beliefs and behaviors regarding GAT, as well as the values and priorities that contribute to their attitude toward this controversial intervention. The results suggest that, just as in other fields, GAT remains a divisive intervention to consider for children with profound disability. Differences in how GCs who support GAT and GCs who oppose GAT rank arguments for or against the practice reveal that although all GCs' primary concern is the well-being of the child, they interpret the benefits, risks, and psychosocial consequences of GAT differently. Two primary differences that arose were that GCs opposing GAT emphasize children's inability to consent to GAT and its potential to infantilize patients, while those who support GAT believe that guardians have the right to make decisions for their child – or that children with profound disability do not have autonomy to infringe upon – and treating patients by their cognitive age is not infantilization. These differences in core beliefs are not likely to be resolved with further debate or discussion. Some respondents reported that their attitude toward GAT may shift toward supporting if GAT's proposed benefits are confirmed but concerns about autonomy and infantilization will not be eliminated even if quality of life improvements are verified. It is likely that the debate surrounding these factors will persist even if data ultimately support GAT's proposed benefits.

Practice beliefs also vary. Similar to Wrigely and colleagues' 2017 study of New Zealand medical professionals, nearly the same proportion of genetic counselors believed GAT should be offered routinely to guardians of children with profound disability as those who reported they would never discuss the option of GAT with a guardian.

However, both groups were in the minority. Although nearly a third of genetic counselors personally opposed GAT, most respondents agreed that the intervention may be appropriate in certain circumstances.

The survey text responses and interviews revealed that, for many genetic counselors, the limiting factor for genetic counselors to support GAT clinically is proof of its risks and benefits. Genetic counselors made suggestions for further research which could support or dismiss the possible benefits GAT offers to patients and their families.

Given the lack of known clinical utility of GAT in genetics at this time, GCs emphasized the value that GCs offer in providing therapeutic support to guardians who struggle with caring for their child. Although GCs may not be able to provide education about GAT and rarely do their teams offer to refer to an endocrinologist, GCs have the training to help guardians explore their needs, support resources, and sources of resilience as they face the future of caring for a child with a profound disability. GCs did suggest, however, that the field would benefit from guidelines to help GCs frame these counseling discussions to best benefit the guardians. Respondents also suggested the development of a toolkit to help GCs find and access resources such as an ethics committee or peer supervision group to support their work when they face difficult or ethically challenging cases. Notably, NSGC provides peer supervision resources as well as ethics consultation services to its members. It may be that these resources are not well known or underutilized by genetic counselors.

The genetic counselors surveyed and interviewed for this study consider medical decisions and parental decision-making in ways that align closely with the Four Topics approach and the Zone of Parental Discretion. Becoming familiar with these tools may be

useful for genetic counselors and other clinicians to better understand and articulate their own methods for considering these topics, as well as to present frameworks for use institutionally or within their teams.

Study Limitations

This study was limited by a low response rate, which restricted quantitative analysis to descriptive statistics. There are further analyses that could have practice implications, such as understanding whether experience with GAT, knowledge of GAT, or demographic characteristics impact one's attitude toward the intervention, or if genetic counselors with different attitudes toward GAT have statistically significant differences in how they address it in clinic. It is also possible that the content of the survey attracted genetic counselors with knowledge of or experience with GAT, skewing understanding of GAT knowledge or how often GAT is raised in genetic counseling sessions.

The interviews were similarly affected by low numbers. Although they offered a more detailed and holistic understanding of the beliefs and practices of genetic counselors GAT discussions, saturation was not reached for the great majority of themes. Seven of the eight genetic counselors who reported clinical discussions of GAT on the survey were interviewed. However, the survey indicated that there are clinics in which GAT discussions are initiated by clinicians, and no genetic counselors from such clinics volunteered to be interviewed. It is also likely that as more genetic counselors counsel guardians about GAT, more diverse responses and considerations will develop.

Responses to survey and interview questions were subject to participants' interpretation of what a GAT counseling session might entail and their own role as a genetic counselor. The study identified two primary perceptions of a genetic counselor's role in GAT counseling: either little to no role, because questions about GAT are highly medical and more appropriate for a physician to answer, or as a psychotherapeutic resource to the guardians considering GAT for their child. It is possible that there were respondents who theoretically subscribe to one of these perceptions, but in practice act on the other. Several survey participants directly questioned the role of a genetic counselor in any GAT discussion using the free text responses. It may be that this question arose in the medical and ethical context of the survey, but in practice a portion of these genetic counselors would use the counseling techniques described by some of the interview participants to engage in the GAT discussion if confronted by that in an actual clinical encounter. From the interviews it is clear that there are some genetic counselors who do not engage or only minimally engage in these discussions, but the frequency of this practice in comparison to therapeutic counseling is unclear.

This study offered a cross-sectional understanding of the attitudes of a subset of pediatric genetic counselors, most of which reported little to no knowledge of GAT before taking the survey. It is possible – even likely – that the beliefs respondents hold toward GAT will change as they learn more about it, experience discussions in their clinic, or as further research regarding its risks and benefits are published.

Practice Implications

These data suggest that although growth attenuation therapy is rarely brought up in genetic counseling sessions, when it is brought up it is often in the context of guardians

looking for a solution and support during a difficult time caretaking. Few genetic counselors feel they have the knowledge of GAT or medical expertise to counsel regarding the utility of the intervention, but many acknowledge genetic counselors' expertise in providing psychosocial counseling to better understand the stressors guardians face as they think about GAT as an option and to provide support as guardians care for their children.

Survey responses indicate that a minority of genetic counselors are aware of GAT as an option for children with profound disability, which introduces a risk of genetic counselors being surprised by the suggestion and unable to offer support when a guardian brings it up in clinic. Both survey and interview responses included those from genetic counselors who would decline or have declined to talk about GAT in a session beyond letting a guardian know that it won't be offered by their institution. Genetic counselors are unlikely to stay abreast of all medical options available to guardians, and to counsel about their utility is considered outside their purview for many genetic counselors. However, genetic counselors should be prepared to offer psychosocial support and counseling when guardians are considering care options for their child, whether the genetic counselor is familiar with or supportive of the options being considered. It may be that additional educational offerings from NSGC for each new procedure is not feasible, but resources to prepare genetic counselors for the psychotherapeutic role of discussing difficult options can help genetic counselors feel more prepared.

Research Implications

This study assesses the reactions toward GAT of clinicians who are on the periphery of the GAT debate and GAT decision-making. Although genetic counselors are

involved in diagnosis and continued care of children with profound disability, they are rarely involved in medical management decision-making. Genetic counselors' value as therapeutic counselors and as the bridge between client families and physicians can prove important when guardians are considering a controversial intervention option for their child, but it is not genetic counselors' opinion on GAT that is likely to shape the GAT debate or its use in the future.

To better understand the state of GAT's use now, over ten years after Gunther and Diekema's first report, a study of endocrinologists' attitudes and practice beliefs is recommended. Endocrinologists are at the forefront of GAT implementation and could offer insight into how institutions choose for whom GAT is appropriate and how or when resources such as ethics committees are used. It is unclear if GAT practice aligns with recommendations from Wilfond and colleagues' working group guidelines or if there is any consistency to its use, and such a study has the potential to reveal the significant subjectivity to its use implied by the present study.

There is an overt gap in the GAT literature regarding guardian experiences making decisions about the intervention. There are isolated cases of parents sharing their stories and case reports of parents who choose to pursue GAT, but no published studies that synthesize the experiences of a large population of guardians who have considered GAT, the thought processes through which they choose to pursue or decline the intervention, or the outcomes of their decision. Pollock and colleague's 2015 study of American endocrinologists reported that nearly 30 physicians claimed to have prescribed GAT to at least one patient. Understanding the guardians' decision-making process and

the process by which other guardians choose to decline GAT will provide important context to the GAT discussion which is currently absent.

Interviewees offered suggestions for further research to better illustrate the risks and benefits of GAT for children with profound disability. GAT has now been prescribed for over ten years, but there have been no reports published to summarize the side effects that have developed in this population and there are no known projects in place to follow patients or controls longitudinally to better understand quality of life benefits. As suggested by one interviewee, a proxy for this study would be to assess differences in years of care at home between children with profound disability and short stature compared to children with profound disability and average or above-average height.

CONCLUSIONS

Pediatric genetic counselors often counsel guardians about diagnosis and prognosis for their child, but rarely do guardians engage them in discussions of GAT as an option to facilitate care. Although genetic counselors largely believe that their role is to offer support and anticipatory guidance to guardians who share the difficulties they face raising a child, many are uncomfortable discussing GAT due to their lack of knowledge of GAT, lack of involvement in medical management decisions, or opposition to the intervention. Until there is clear evidence to support or reject GAT's utility for children with profound disability, genetic counselors should continue to cultivate the skills to offer accurate empathy and therapeutic counseling for clients who are facing difficult decisions or obstacles. The development of professional resources to guide genetic counselors as they counsel on controversial topics or face challenging ethical cases will benefit both the genetic counseling field and the clients it serves.

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BIOGRAPHY

Katherine was born in 1992 in Pennsylvania, USA. She moved to Illinois during childhood, where she cultivated a love for science and genetics.

She did her undergraduate work at Miami University in Ohio, majoring in Zoology and Organizational Communication and co-majoring in Sustainability. During her undergraduate studies, Katherine worked under the direction of Drs. Nancy Solomon and Brian Keane to investigate the relationship between microsatellite AVPR1, vasopressin receptor expression, monogamy, and reproductive success in the prairie vole, as well as the relationship between distance, dispersal, and genetic relatedness in this species.

Katherine joined the Animal Programs department of Walt Disney's Animal Kingdom in 2014 to further study animal behavior. There she realized her love for education and passion for working with people. During this time, she also volunteered as a group facilitator for Growth from Grief, a program to help children who are mourning the loss of a loved one to explore their grief in healthy, constructive, supportive ways.

In 2016, Katherine began her ScM in Genetic Counseling with the Johns Hopkins University/National Human Genome Research Institute program. During her program, she served as a support group facilitator for the Proteus Syndrome Foundation conference and she interned with Concert Genetics, collecting and analyzing data to assess the use of race, ethnicity, and ancestry data collection across the genetic testing industry.